INTRODUCTION

Acute neurological incidents, for example, stroke, traumatic brain injury, infection or cardiac arrest are sudden, often unforeseen and always life-changing. When people have been hospitalised for such events, the time eventually comes when they leave hospital and start to live the rest of their life in a community setting. The first author in this chapter is a consultant rehabilitation physician who has been working for more than 20 years with people who have experienced such events and are living in the community. The co-author is a physiotherapist who has also worked within community settings. Their clinical paths have occasionally crossed over the years but, when they decided to write this chapter together, opportunities arose to discuss how interpersonal relationships in professional clinical practice affected, and were affected by, the reality and complexity of community-based rehabilitation for people who had experienced brain injury. The following narratives concentrate on the reality of life experienced by these people and the elements of relational healthcare considered to be important for them to be able to live well in the community again.

SETTING THE SCENE

There has been a growing awareness of the long-term difficulties that many people with traumatic brain injury (TBI) have in regaining a meaningful life. A significant number of individuals continue to have trouble in their daily lives after they leave the rehabilitation setting (Tait, 2003). This has led some TBI programs to alter their focus towards working in the community, rather than within the rehabilitation centre.

Community-based rehabilitation programs for people with TBI differ from the traditional centre-based models in several ways. Firstly, the emphasis has shifted from ameliorating impairments and disabilities towards re-establishing everyday activities and thereby increasing participation in normal life. The process of assessment involves identifying roles and skills important for a person with TBI within community contexts, as assessed from the perspective of that individual, close others, employers and educators.

Psychological support is required to assist the person with TBI and close others in coming to terms with lasting personality and lifestyle changes and
forming a new post-injury identity. Ideally, follow-up contact is maintained over an extended period to provide support in dealing with new problems as they arise with changing circumstances. Where the person with TBI is not immediately able to return home from hospital, this therapeutic input may be provided within a residential “Transitional Living Program”. These programs provide therapy to enhance independent living skills and interpersonal skills, and eventually support the move to independent living, with continuing attendant care or other supports as necessary.

A more common model of service provision is that of a “community-based team”. This generally comprises occupational therapy, speech pathology, clinical and/or neuropsychology, physical therapy, social work services, vocational counselling and educational assessment as needed. Generic services in the local community may be utilised. Assessment, goal setting and interventions are carried out within the relevant settings in the community. Interventions may involve repeated practice to establish routines, development of compensatory strategies, or modification of a task or environment to maximise successful task performance. Extra assistance may be employed.

TBI has a significant impact on caregivers, and on the family as a whole. Family members provide most of the ongoing support of a practical, social and emotional nature to the person involved, and family interactions are an important determinant of the injured person’s psychosocial adjustment. Families need to be involved in the rehabilitation process, and to have access themselves to supportive counselling and assistance in finding and dealing with service agencies and managing financial and legal issues. The adjustment process for families is likely to be lengthy. Multi-family group interventions may provide opportunities to share experiences and enhance family functioning and social integration for caregivers. Access to family therapy services can assist families who have difficulty in grieving, or in adjusting to the new roles and expectations that the injured individual will have within the family. All forms of family support need to be available over the lifespan of the person with TBI. In particular, provision of support in managing behavioural issues following TBI is of paramount importance. Family caregivers report this to be the greatest source of stress when caring for their injured relatives.

MAKING A SAVED LIFE WORTH LIVING

What you see in the news does not show the years of effort ahead for the person who has had a brain injury, their family and the changed life that eventuates. Rehabilitation is “what happens next” after a person suffers a disabling injury or illness. It does not save lives, but can make the saved life worth living.